BELIEF AND EMOTIONAL FACTORS OF THE RENAL TRANSPLANTEE: ORAL HISTORY

CRENÇA E FATORES EMOCIONAIS DO TRANSPLANTADO RENAL: HISTÓRIA ORAL

ABSTRACT

Objective: to report the oral history of life, belief and emotional factors involved in the longevity of a renal transplant patient for more than ten years. Method: a qualitative, exploratory study carried out at the residence of a patient suffering from hemorrhagic dengue, who developed severe renal impairment in both kidneys. A structured interview script, the field notebook and the recording made with a cell phone in March 2018 were used as a collection instrument. The result is presented as a textual testimony of the patient.

Results: point to the importance of belief, emotional factors and good quality of life for patient recovery. On the other hand, there is the importance of having a well-trained Nursing as well as multiprofessional work.

Conclusion: renal disease, which has several phases, which can lead to renal transplantation, brings a great challenge to the health system and, to the patient, the need for physical and emotional overcoming, being a disease that demands actions of all the society.

Descriptors: Kidney Transplantation; Quality of Life; Severe Dengue; Renal Insufficiency; Culture; Peritoneal Dialysis.

RESUMO

Objetivo: relatar a história oral de vida, a crença e fatores emocionais envolvidos na longevidade de uma paciente transplantada renal há mais de dez anos. Método: estudo qualitativo, exploratório, realizado na residência de uma paciente vítima de dengue hemorrágica que evoluiu para a insuficiência renal grave em ambos os rins. Utilizou-se, como instrumento de coleta, um roteiro de entrevista estruturado, o caderno de campo e a gravação feita com telefone celular no mês de março de 2018. O resultado se apresenta em forma de depoimento textual da paciente.

Resultados: apontam para a importância da crença, dos fatores emocionais e da boa qualidade de vida para a recuperação do paciente. Por outro lado, tem-se a importância de uma Enfermagem bem treinada como, também, do trabalho multiprofissional.

Conclusão: a doença renal, por possuir várias fases, - que podem levar ao transplante renal - traz, ao sistema de saúde, um grande desafio e, ao doente, a necessidade de superação física e emocional, sendo uma enfermidade que demanda ações de toda a sociedade.

Descriptors: Transplante Renal; Qualidade de Vida; Dengue Hemorrágica; Insuficiência Renal; Crença; Diálise Peritoneal.

RESUMEN

Objetivo: relatar la historia oral de vida, la creencia y factores emocionales involucrados en la longevidad de una paciente transplante renal desde hace más de diez años. Método: estudio cualitativo, exploratorio, realizado en la residencia de una paciente trasplantada renal desde hace más de diez años. Se utilizó, como instrumento de recolección, un guión de entrevista estructurado, el cuaderno de campo y la grabación hecha con teléfono celular en el mes de marzo de 2018. El resultado se presenta en forma de testimonio textual de la paciente.

Resultados: apuntan a la importancia de la creencia, de los factores emocionales y de buena calidad de vida para la recuperación del paciente. Por otro lado, se tiene la importancia de una enfermería bien entrenada como, también, del trabajo multiprofesional.

Conclusión: la enfermedad renal, por tener varias fases, - que pueden llevar al trasplante renal - trae, al sistema de salud, un gran desafío y, al enfermo, la necesidad de superación física y emocional, siendo una enfermedad que demanda acciones de toda la sociedad.

Descriptors: Transplante de Riñón; Calidad de Vida; Dengue Grave; Insuficiencia Renal; Libertad Religiosa; Diálisis Peritoneal.
INTRODUCTION

It is known that the success of the first transplants, made among genetically identical individuals, dates back to the 1950s in Boston, the cross-match to know which the best receptor in the attempt to detect preformed cytotoxic antibodies was a determinant factor in the success of renal transplantation.³

It is observed that in 1963, only seven patients survived after six months of transplantation. However, renal transplants currently have a satisfactory success rate, and thousands of transplants with good life prospects are performed in all major medical centers.

It should be noted that there is a constant and growing demand for organ transplants throughout the national territory. The first transplants performed in Brazil date back to the 1960s, but the National Transplantation System (NTS) was created only in 1996, due to a great demand for organ and tissue transplants throughout the country. Published on February 4, 1997, Law 9,434, which provides for the removal of organs, tissues and body parts for this purpose, ² establishes the gratuity and defines that the recipient will not have any compensation if the transplant is canceled, not performed or does not obtain the result expected by the teams, and the Federal Medical Council, through Resolution 1480/97, defines the definition of brain death.

It is explained that chronic kidney failure (CKF) consists of renal damage with progressive and irreversible loss of renal function. In its later phase (called the terminal phase of CKF), the kidneys can no longer maintain the normalcy of the internal environment.³ Today, CKF is considered a public health problem that is independent of race, culture, age group or socioeconomic group.⁴ CKF is a disease that presents no prospect of improvement by determining relevant public health problems due to the high rate of morbidity and mortality.⁵

It is evidenced that the chronic renal patient constantly lives the conflicts generated by the dependence of the technologies making him sometimes feel alive, others, semimortal, as a consequence of the substitutive renal therapies that save the lives, at the same time that transforms them, subjecting the sick people to the extreme suffering experienced in the censorship of the will and the non-power and preventing of the life to be realized in the human and social acts.⁶

OBJECTIVE

- To report the oral history of life, belief and emotional factors involved in the longevity of a renal transplant patient for more than ten years.

METHOD

This is a qualitative, exploratory, Oral History of Life study about a renal transplant patient for more than ten years. The study was carried out at the residence of the patient suffering from hemorrhagic dengue, with progression to severe renal insufficiency of both kidneys. She received the brother's left kidney. As a tool for data collection, a structured interview script was chosen, as well as a photographic record, field notebook and mobile recording. Data collection was started after approval of the project by the FACENE / FAMENE Ethics and Research Committee.
Committee. It was held in March, in a day and time combined between the researchers and the interviewee, in three moments:

a) Pre-interview. It corresponds to a preparation in which the first contacts and approximations were made with the collaborator (patient) and with their context, besides being the moment when the research project was explained and the Free and Informed Consent Term (FICT) was presented. The patient was informed duly emphasizing that her rights would be safeguarded and their anonymity, protected;

b) Interview itself. The interview was recorded by a cell phone. The interview was the focal point of the study and was characterized by an affable environment, so that the person could narrate their history without constraints, although, in interaction, the interferences of the researchers were minimal. At that moment, the collaborator spoke about her feelings, emotions and reflections and clarified to her about the importance of their contribution, as well as explained the steps of the project and the ethical care adopted;

c) Post-interview. After the interview, the oral report was transformed into written text, making it available for publication, through careful analysis of the recording, as Meihy suggests in three steps.9

First step: Transcription is the stage of the rigorous, long and exhaustive process of initial passage from oral to written. For some researchers, it is an operation of a purely technical nature, sometimes relegated to others. However, from the perspective presented, transcription is of great importance for the construction and analysis of life histories, mainly because of its repetitive nature.

Second stage: textualization is the stage in which the questions are suppressed and added to the answers, becoming the exclusive domain of the collaborator assuming the first person as the only person. During this stage, the narrative gets a little reorganization to become clearer. The vital tone is then chosen, which, is a phrase to be put in the introduction of the History of Life, because it represents a moral synthesis of the narrative. The objective is to enable a better understanding of the narrative.

Third stage: transcription is the stage in which one acts in the testimony in a broader way, inverting the order of paragraphs, removing or adding words and phrases and, finally, performing the “language theater”. It is sought to recreate the context of the interview in the written document. More than a translation, it tries to elaborate a synthesis of the sense perceived by the researcher, besides the narrative and performance of the collaborator. The process is terminated with the validation by the collaborator (patient) of the final document. There is, therefore, explicit interference of the researcher in the text, which is redone according to suggestions, changes and hits combined with the collaborator in the moments of conference of the textual narrative. In this procedure, it becomes vital to legitimize the interview by the collaborator.

In this study, the ethical aspects recommended by Resolution CNS 466/2012 were respected in art. III.9

RESULTS

Refers to A.K, 30, natural and resident in João Pessoa (PB) with his mother and brothers in the neighborhood of Valentina. Her illness began in 2002, when she had hemorrhagic dengue that led to kidney failure. During the interview, she was very happy and talkative, willing and interested in collaborating with the research.

Before kidney failure, I was a normal person, worked and had my sporting activities, I was a handball player. He taught at a children's school and still taught tutoring during the week. Everything changed in 2002, when I was stung, for the fourth time, by the dengue mosquito, Aedes aegypti. I was in school when I started to feel bad. I started having vomiting and an intense itching in my body. I had had dengue three times, but they had been normal; the most itching was the itching. And, the fourth time, the disease presented the hemorrhagic condition. I have black skin and yet I saw many red patches on the body in addition to nasal and gingival bleeding. I was hospitalized, I took several medications and the bleeding was controlled. After 15 days, at home, after leaving the hospital, I began to experience symptoms related to paralysis of the kidneys. I started to get swollen and with a big belly, the clothes did not fit. I had a fever, I began to feel pain in the back that went down to the legs. It was when a nurse friend of our family who worked in the hemodialysis sector of a hospital suspected that I had kidney impairment. She indicated a doctor, known to her, and the same day I went to meet him. Those who looked at me already understood, I was not normal. The attending physician brought the result of the blood test, and the urea and creatinine rates were greatly altered. I had a strong anemia and felt pain in my legs. And the diagnosis of acute renal failure came. I was referred to

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the referral hospital on hemodialysis. When I got there, I made up all the tests and the initial diagnosis was confirmed. At that moment, I had a lot of liquid accumulated and felt like going to the bathroom all day, although I could not urinate. Soon after, I began to feel the taste of urine in my mouth. And from there, I started to do peritoneal dialysis, an alternative for hemodialysis. I started my dialysis in the hospital and after a year of treatment I was transferred to a kidney treatment center where I spent five years. Throughout the treatment, I took blood bags because of my anemia, which was very strong. In the first year, at the beginning of the treatment, I had to undergo a minor surgery where they implanted a catheter in my belly that allowed access to the peritoneum to do the dialysis. I refused to put the catheter in the neck and said no treatment on the machine. A psychologist was called to talk with me and I visited other patients on hemodialysis. My first dialysis was made in the hospital with the help of an emergency nurse. It was very important in my life because the whole period I spent in the hospital was of negativity. Before returning home, we had classes, for a week, to learn how to do the procedure. When I got home, my mother did the first dialysis procedure. She could not stand it and fainted at my feet, I was in a panic. The peritoneal dialysis process facilitates infection and many patients are unable to stay at home. In five years on dialysis, I have never done the procedure alone. The dialysis happened in a room of the house, reserved, closed, and only I and the companion. The room could not have furniture, just the bed and a small table for the diapers, 70% alcohol bottles, disposable masks and a stand for the serum. During the procedure, one liter or two liters of solution may be used. The amount of solution depends on the swelling and also the discomfort of the patient. The diapers were used soaked in 70% alcohol for preventive purposes. The procedure is quite contaminated, hence the use of masks. The solution would go through the catheter every four hours to do the work the kidneys stopped doing. In the face of my experience, I usually say this: when the kidneys paralyze, they begin to fiddle with all the other organs. The cardiac and pulmonary function is impaired, the bowel is deregulated so that the patient does not have solid stools, and there is a lot of diarrhea and vomiting. My heart was grown and I lost a lot of weight. I even weighed 28kg when my normal weight was 45kg. My face was puffed up and swollen. Besides, I stopped menstruating. I only went back to menstruating after the transplant. And during the dialysis treatment, the idea of transplantation came up. They came to ask me what I thought of the idea. That's when you see how serious it is. You think: it paralyzed an organ, I'm going to die. I could not even drink water, everything was limited, the amount I took fit in those little coffee cups, to take the pills. All my family have taken the compatibility test. And all were compatible. We are a tightly knit family, I can not complain about that. I am Catholic, devout of Our Lady Aparecida, and it was the faith that made me go through all this. Sometimes I wanted to surrender, I was already dying and I wanted to give up. Then my mother encouraged me, my giver encouraged me. I stood by the corners of the withered walls; I spent two depressing months, not wanting to leave the room neither to eat, nor to take a shower, much less talk to anyone. I'm going to tell a story to those who have faith. My mother called me to the coronation of Our Lady Aparecida in the month of May, the month of Mary. I was very weak that day, but even so, we left home very early and arrived for the coronation at 7:00 p.m. When we arrived, no one had arrived at the church and we kept praying for the transplant. The hospital and the medical team were still lacking for it to be performed. It was May 31, the last day of the month of Mary, and a church official withdrew the rosary that was being prayed every day in the image and changed it. She left the church and left us sitting there. Some time later, she returned to the church and handed me the rosary. I said the following when giving me the rosary: "Our Lady Aparecida sent you to deliver!" I swear to you: when that third stopped in my hand, I felt a sense of floating. A warm sensation from head to toe … As if a sea wave was washing everything bad. I walked home, different from how I came, dragged. I put the third arm in the arm the same day she gave it to me. Upon arriving at our house, my mother did my change of clothes and said, "You're right, you get ready for this to be the last exchange I make on you." I was already asleep sitting up because of the liquid that was suffocating me. And I saw Our Lady Aparecida walking to and fro inside this room. The other day, on Monday, the phone rang and the attendant said that on Tuesday, - the next day - I would go to São Vicente de Paula Hospital, because, on Thursday, my transplant would be performed. A team from Pernambuco would do my surgery. Another miracle was my pressure, which only went down when I took four types of pressure tablets and on that day I went, I did not take any. My brother made the transplant and, well, in the name of Jesus, he does not take anything. I take my medications to avoid rejection ever since. I was hospitalized for one month, already transplanted, and my mother was...
Renal replacement therapy (RRT) is indicated for severe patients and has three different types: hemodialysis (HD), peritoneal dialysis (PD) and renal transplantation. The HD removes solutes and fluids with the help of an arteriovenous fistula and an artificial filter (capillary or dialysis membrane). The RRT is performed three times a week and causes the patient to lose independence since the session lasts up to four hours. PD uses the peritoneal surface itself as a membrane and is performed at home. The patient's quality of life depends on several factors such as satisfaction with life, good health, housing, employment, education and leisure, and these parameters are the subject of the most profound scientific research in the search for patient's health.13

[...After 15 days, at home, after leaving the hospital, I began to experience symptoms related to paralysis of the kidneys. I started to get swollen and with a big belly, the clothes did not fit. I had a fever, I began to feel pain in the back that went down to the legs. It was when a nurse, our family friend, who worked in the hemodialysis sector of a hospital, suspected that I had kidney impairment [...].]

It is said that, according to the biomedical model, renal transplantation is the best treatment for renal failure. Among the arguments are: improving the quality of life of patients, reintegrating previous productive activities, and the social cycle that is lost by the patient. Transplant therapy is more effective because it causes less economic impact to both the patient and the state. The costs of hemodialysis or peritoneal dialysis for the government exceed the cost of surgery, and the debilitating factor is an aggravating factor, since the patient stops exercising their work activities.14

[...]I refused to put the catheter in my neck. In fact, the doctor asked if I was a Jehovah's Witness and if that condition was preventing me from undergoing hemodialysis. I said no and I would not do the treatment on the machine. A psychologist was called to talk with me and I visited other patients on hemodialysis. And from there, I started to do peritoneal dialysis, an alternative for hemodialysis [...].

It is emphasized that the nurse is the element that is in greater contact with the patient, present before, during and after the dialysis. It should be alert to detect possible complications during dialysis and to take the necessary measures promptly and quickly, since the life of the patient may depend on many of these measures. Hypotension and shock, usually due to hypovolemia, may occur
during dialysis; cardiac arrest; cold and tremor, nausea and vomiting; brain symptoms and cannula problems such as decreased blood flow.15

[...] The nursing of the dialysis service was very important in my life because the entire period I spent in the hospital was of negativity. Before returning home, we had classes, for a week, to learn how to do the procedure [...].

It is understood that, despite the choice of peritoneal dialysis, older patients are less indicated for PD, since it requires the help of a third person. This modality of therapy increases patient independence and is a valid option for hemodialysis, since it poses technical challenges and limitations inherent in patients such as hypotension and arrhythmias, in addition to that the PD regimen is physiologically smoother. Risks of cognitive loss and dementia were reported in greater numbers among HD users. Added to this, we also have the great cost brought by the displacements to the HD units.16

[...] When I got home, my mother did the first dialysis procedure. She could not stand it and fainted at my feet; I was in a panic. The peritoneal dialysis process facilitates infection and many patients are unable to stay at home. In five years on dialysis, I have never done the procedure alone. The dialysis happened in a room of the house, reserved, closed, and only I and the companion. The room could not have furniture, just the bed and a little table for the diapers, 70% alcohol bottles, disposable masks and a stand for the serum.

It is revealed that only 10% of Brazilians use peritoneal dialysis, with death and peritonitis being the main causes of treatment withdrawal and Staphylococcus aureus, the main infectious agent in Brazil. Peritonitis is mainly related to inadequate technique during bag handling or catheter connection. Although it is rare, peritonitis can lead to death and is considered a contributing factor in 16% of cases.17

It is noticed that, although the main cause of death in the population, in general, is due to cardiovascular diseases, when compared in patients who undergo renal replacement therapy (RRT), this value increases exponentially. This can be explained by the fact that, in addition to patients with renal disease who are influenced by traditional cardiovascular risk (systemic arterial hypertension, Diabetes Mellitus, obesity), which is not seen by the patient in this study, patients with chronic kidney disease are influenced by new factors due to the decline of renal function. These factors include:

- anemia, hypervolemia, albuminuria, increased oxidative stress, chronic inflammation, and changes in calcium and phosphorus metabolism. Likewise, changes in chronic kidney disease are considered risk factors for cardiovascular diseases.18

[...] The cardiac and pulmonary function is impaired, the intestine becomes unregulated so that the patient does not have solid stools and there is a lot of diarrhea and vomiting. My heart was grown and I lost a lot of weight. I even weighed 28 kg when my normal weight was 45 kg, my face was puffed up and swollen.

It is recalled that there are some treatment alternatives for the chronic renal patient, such as peritoneal dialysis, hemodialysis and renal transplantation, although none are considered curative, but rather substitutive. Among them, renal transplantation is considered the best method for the terminal chronic renal patient because it promotes better quality of life and lower mortality.19

It is evidenced that psychological evaluation includes the recipient and donor of the kidney. In addition, there is family support. The psychologist's function ranges from treatment to transplantation. And it helps the patient to face a difficult and discouraging journey. In cases where the donor is alive, the ideal is that it is spontaneous, that there is no pressure in any way. The psychological interview with the donor aims to clarify the whole surgical process and also the recovery, preparing it for possible rejection of the kidney by the recipient.20

[...] And during the treatment of dialysis the idea of transplantation came up. They came to ask me what I thought of the idea. That’s when you see how serious it is. You think: it paralyzed an organ, I’m going to die. I could not even drink water, everything was limited, the amount I took fit in those small coffee cups to take the tablets.

It is emphasized that dependence on dialysis and change in lifestyle imposed by kidney disease can trigger behavioral changes that include decreased libido and self-esteem. In addition, there are other factors that may contribute to behavioral changes such as fatigue, anorexia and sleep disorders.21

[...] I stood by the corners of the walls, withered. I spent two depressing months, not wanting to leave the room or to eat, or to take a shower, much less talk to anyone. [...] It was the faith that made me go through all this. Sometimes I wanted to surrender, I was already dying and I wanted to give up. Then my mother encouraged me, my giver encouraged me.
It is understood that, in the dimension of vitality, these results reflect the feeling of fatigue and exhaustion corroborating researches on fatigue in chronic kidney patients on hemodialysis. Fatigue is significantly associated with the presence of symptoms such as sleep problems, physical limitations and depression.5

It is evident that, with regard to the Christian faith, those who have faith in God (94%) predominated, and religious beliefs function as cognitive mediators, by interpreting adverse events in a positive way, and may favor the adaptation of people to the health condition.22

[...I] stayed one month in the Hospital, already transplanted, and my mother was my great companion.

The physical domain of quality of life before and after renal transplantation revealed a significant improvement in all aspects analyzed, reducing the impact of pain and perception on the need for treatment, improvement of energy, satisfaction with sleep, ability to move around, ability to perform day-to-day tasks and ability to work.21

[...the hunger was slowly coming back and my weight began to adjust. In two months post-transplant, he was weighing 50kg. When I operated, I was weighing 28 kg. In 72 hours of surgery, I have returned to urinate and it was one of the biggest emotions after five years of suffering.

CONCLUSION

It is understood that the technical-scientific advance has contributed to the fact that renal transplantation is considered the best option for patients with chronic renal failure. Transplantation improves patients’ quality of life, since it reintegrates productive activities and the social cycle that was lost by the patient. It was possible to identify, through this study, that factors related to belief and also to the support of family and friends can be determinant in the recovery of the patient. It should be stressed that the research was of great value not only for those who are part of the team, but also for the National System of Organ Transplants, since conducting research of this kind promotes an increase in the knowledge of the professionals and students involved in it or who use it to have a referential, in addition to contributing to teaching, research, extension and assistance.

REFERENCES

Belief and emotional factors of the...